

DEVELOPING LAW AND ETHICS

The Convention on the Rights of Persons with Disabilities

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The most recent expression of the human rights applicable to people living with mental illness is the *Convention on the Rights of Persons with Disabilities* ('the Convention').¹ The Convention is a comprehensive statement of international human rights law.² It does not purport to create new rights.³ However, as the first international convention to be drafted following the adoption of the *Vienna Declaration and Program of Action*, and with the collective and collaborative action from people with disability, it offers a new articulation of how human rights are conceived, expressed and realised. In this sense, it marks a new era in disability rights.⁴

Does the *Convention* impose obligations that challenge the delivery of mental health services? Some people in the disability community argue that both involuntary medical treatment and substituted decision-making are contrary to *Convention* principles.⁵ Others argue that the *Convention* does not prohibit these practices. Adopting the latter view, Australia lodged an interpretive declaration together with its instrument of ratification indicating that it considered compulsory treatment and fully supported or substituted decision-making to be permissible under the *Convention*, but only as measures of last resort.⁶ At the centre of the current debate are Article 17, on the right to respect for physical and mental integrity, and Article 12 on the right to equal recognition before the law.⁷

On 21 October 2009, the Committee on the Rights of Persons with Disabilities ('the CRPD') convened a 'Day of General Discussion on Article 12 – The Right to Equal Recognition Before the Law'.⁸ The outcomes of the day of discussion are yet to be made public. This article is offered as a contribution to the ongoing debate. It argues that the right to be free from interference with one's physical and mental integrity as expressed in Article 17, in conjunction with the recognition of the right to equal recognition before the law expressed in Article 12, redefines the ethical and legal standards that should guide the care of treatment to people with mental illness. The combined effect of Articles 12 and 17 is to emphasise the importance of supported decision-making, and refute the acceptability of involuntary medical treatment.

Article 17 and the Prohibition of Torture

Article 17 is the shortest Article in the *Convention*. It provides that:

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

This truncated text is a product of a 'negotiated silence' aimed at reinforcing the implied prohibition against involuntary treatment.⁹

According to the United Nations Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the inclusion of Article 17 in the *Convention on the Rights of Persons with Disabilities* enables previously accepted practices in the mental health care and treatment to be reframed as cruel, inhuman or degrading treatment or punishment.

It is established law that severe maltreatment, neglect, or humiliation of patients may constitute cruel, inhuman or degrading treatment or punishment and violate human rights. Conversely, it is usually assumed that therapeutic practices, however confronting, are not captured by the prohibition. The comments of the Special Rapporteur question this distinction. He raises the possibility that intrusive medical intervention may infringe the rights enshrined in the CRPD. This argument suggests the need for a re-evaluation of many 'taken for granted' practices in the delivery of mental health services. Furthermore, the complexities of the psychiatric context indicate that human rights evaluations should proceed on a case-by-case basis. These evaluations must also keep in mind the deeply discriminatory attitudes and practices that shape the care and treatment of people with disabilities.

Prohibition against torture and current mental health treatments

The Special Rapporteur lists the following common mental health treatments and practices as likely to constitute an infringement of *Convention* rights:

- poor conditions of detention;
- the use of restraints, including the use of medication as a form of chemical restraint;
- the administration of drugs as punishment;
- the use of seclusion and isolation;
- experimentation or experimental treatment without consent;¹⁰
- forced treatments that are intended to correct and alleviate particular impairments;
- intrusive or irreversible treatment, such as lobotomy and psychosurgery;

REFERENCES

1. *Convention on the Rights of Persons with Disabilities* opened for signature 13 December 2006, 46 ILM 443 (entered into force 12 May 2008) ('*Disabilities Convention*').
2. For a comprehensive discussion of the drafting of the *Convention* see: Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2007) 34(2) *Syracuse Journal of International Law and Commerce* 563.
3. Louise Arbour (UN High Commissioner for Human Rights), Press release on the Ad Hoc Committee's adoption of the International Convention on the Rights of Persons with Disabilities, New York, 5 December 2006.
4. Bernadette McSherry (ed), 'International Trends in Mental Health Laws' (2008) 26(2) *Law in Context*.
5. See World Network of Users and Survivors of Psychiatry: <<http://wnusp.rafus.dk/>>.
6. Australia's Interpretive Declaration of 17 July 2008 relevantly provides that 'Australia declares its understanding that the *Convention* allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards... Australia further declares its understanding that the *Convention* allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguard.'
7. For discussion of Article 17, see Bernadette McSherry, 'Protecting the Integrity of the Person: Developing Limitations on Involuntary Treatment' (2008) 26(2) *Law in Context* 1.
8. Supporting materials for the day are available at <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD21102009.aspx>>.

The implementation of supported decision-making strategies for people with mental illness will similarly require the development of clinical protocols that address the questions of independence and undue influence, to work toward the creation of a culture of patient-centred decision-making.

- forced abortion or sterilisation without free informed consent;
- unmodified electroconvulsive therapy;
- modified electroconvulsive therapy without free and informed consent;¹¹
- forced psychiatric interventions that amount to political or social repression;
- forced and non-consensual administration of psychiatric drugs, and in particular of neuroleptics, for the treatment of a mental condition, especially in the presence of extreme and debilitating side effects;
- involuntary commitment to psychiatric institutions on an arbitrary basis;¹² and
- violence, including sexual violence.¹³

Many of these practices or experiences are not uncommon in mental health care in developed western nations. Of particular note is the inclusion of arbitrary involuntary detention for the purposes of imposing involuntary medical treatment.

Side effects and therapeutic content of mental health treatments

People living with mental illness give further substance to the argument that forced treatment may constitute an infringement of Convention rights by drawing attention to the extreme side effects of psychotropic medications. Evidence of this nature questions the therapeutic basis of interventions by challenging the proportionate relationship between the therapeutic value or efficacy of an intervention and the burden of the side effects the treatment may induce. People with mental illness argue that psychotropic medications mask, rather than relieve, the symptoms of mental illness. Because the dulling or sedative effects of medications often mask the expression of the symptoms, these medications may be experienced as a form of chemical restraint. Conversely, some psychotropic medications produce disabling and distressing symptoms or side effects that mimic the symptoms of mental illness.¹⁴ In these instances the debilitating side effects of the medication may be interpreted by mental health professionals as evidence of continuing or escalating mental illness, giving rise to a cyclical escalation of treatment and debilitation. Ultimately, accounts of the experience of taking psychotropic medication challenge standard medical practices and question the efficacy of pharmacological interventions. These arguments are a plea for the development of an improved evidence base for the delivery of informed, individualised treatment.

Free and informed consent and the question of capacity

A clear emphasis in the Special Rapporteur's comments is that medical treatment must be provided with the free and informed consent of the person. In his view, forced interventions of any kind, particularly those that are tainted by discrimination, lack therapeutic content, or give rise to unacceptable side effects, may constitute torture or cruel, inhuman or degrading treatment.

Emphasising the operation of the principle of free and informed consent in mental health care raises fundamental questions about the assessment of capacity. Amita Dhanda argues that there are three distinct approaches to the assessment of capacity in western systems of law.¹⁵ She describes these as: the status test; the function test; and the outcome test.

The status test assumes capacity on the basis of defined categories. Formulations of law that follow this test disqualify persons with certain attributes from the performance of designated legal tasks or functions. Persons who are excluded by this type of law are typically persons with psychosocial, intellectual, or physical disabilities. Judicial considerations of status-based formulations of law are generally confined to determining the presence or absence of disability. Judicial intervention in this instance tends to focus on whether the disability label or diagnosis was affixed with due process.

Reason, or function-based tests rest on an assessment of whether the person can understand the nature, significance and consequences of certain actions or advice. Using the reason or function test, a court may deny legal capacity to a person who is unable to understand the nature of a contract or is unable to understand that an act is wrong or contrary to law. These tests are the most commonly applied in health contexts as the basis of a person's capacity to consent to medical treatment.¹⁶ Function-based formulations are intended to turn attention to the quality of understanding that is demonstrated by the person. However, Dhanda describes research in a number of jurisdictions that shows that the function test often operates in a similar way to the status test. That is, once the presence of a disability or psychological disorder is established, it is assumed that the person lacks capacity.¹⁷

The third test assesses the outcome of the reasoning process. On this model, the attribution of incompetence or incapacity is made on the basis of the decision

9. Amita Dhanda, 'The Convention on the Rights of Persons with Disabilities', Paper presented at the Conference Workshop at ANZAPPL Annual Congress, October 2008; Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2007) 34(2) *Syracuse Journal of International Law and Commerce* 563, 608.

10. Experimental treatment may be deemed unacceptable on the basis that it constitutes torture or cruel, inhuman or degrading treatment even when consent has been provided.

11. In this case, informed consent must include information about the secondary effects and related risks such as heart complications, confusion, loss of memory and even death.

12. Involuntary detention may be arbitrary where the criteria for involuntary admission includes only the diagnosis of mental disability coupled with additional arbitrary criteria such as being a 'danger to oneself and others' or in 'need of treatment'.

13. Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Special Rapporteur on Torture), *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, delivered to the General Assembly*, UN Doc A/63/175 (28 July, 2008), 52–69.

14. Nancy Covell et al., 'Distress with Medication Side Effects Among Persons with Severe Mental Illness' (2007) 34 *Administration and Policy in Mental Health and Mental Health Services Research* 435.

15. Dhanda, above n 9, 432. See also Amita Dhanda, 'The Right to Treatment of Persons with Psychosocial Disabilities and the Role of the Courts' (2005) 28 *International Journal of Law and Psychiatry* 155, 157.

16. *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402; *Secretary, Department of Health and Community Services v JMB and SMB* (1992) 175 CLR 218 (*Marion's case*); *In Re A* (1993) 16 Fam LR 715, 719 (Aix).

17. Dhanda, above n 9, 432.

arrived at by the person with a disability. Dhanda argues that the effect of this test varies depending on the social acceptability of the decision. For example, if a person accepts psychiatric treatment, he or she is deemed to have capacity and is admitted to a voluntary treatment program. If the person decides to refuse recommended medical treatment he or she is deemed to lack capacity on the basis that he or she lacks insight into the problem of her illness and is unable to recognise the benefits of treatment. McSherry refers to this as the 'Catch 22' of medical care.¹⁸

Dhanda concludes that each of the three approaches engage in a circularity of reasoning that denies people living with mental illness participation in the decisions that affect them, and entrenches the assumption that persons with mental illness are incapable of making decisions.¹⁹ While the function-based test may be able to operate effectively in the absence of embedded and systemic discrimination, the difficulty remains that where any refusal of medical treatment is taken as evidence of a failure to reason, regardless of the merit of the refusal, application of the function test will not reflect an adequate exercise of the ethical obligation of practitioners who seek to comply with Convention principles.

The Convention addresses the capacity/competence debate by assuming that people with disabilities are capable of exercising capacity, while accepting that some persons will require the provision of sufficient support to enable them to meaningfully exercise the same rights as other members of the community. Requiring the provision of support recognises that capacity is a variable human attribute. All persons, whether or not they have a disability, are more or less able to reason and understand the content and consequences of a course of action depending on how much information they receive, in what form and context the information is received, how much time is provided to process the information, and how much opportunity there is to discuss or test the information with trusted persons. This is especially so in relation to health information.

Capacity and supported decision-making

The injunction to support the exercise of legal capacity is found in Article 12(3) of the Convention:

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

The full meaning of the principle of supported decision-making, in practical terms, is yet to be settled. The World Network of Users and Survivors of Psychiatry ('WNUSP') argues that supported decision-making begins with accessible communication and can extend to long term support relationships.²⁰ In the latter case, the WNUSP suggests that state parties should develop standards governing the conduct of supporters. The standards should include the obligation to respect the rights, will and preferences of the person, and the obligation to refrain from conflict of interest and undue influence. The WNUSP argues that the standards

should be established and made known to providers of support and people receiving support.²¹ Regardless of its form, the definitive feature of supported decision-making is that control over decision-making rests with the supported person.

Health facilities can contribute to the development of measures that effectively support individuals to exercise their legal capacity. Strategies that are currently in place to assist people negotiate the mental health system will remain useful; for example, enabling individuals nominated by the person to participate in care and treatment decisions. In addition new strategies may include the:

- education of mental health professionals around the concept of informed consent and their obligations in law;
- education of mental health professionals around the processes of reasoning;
- enhanced recognition by the institution of informal and formal support relationships;
- appointment and involvement of advocates in decision-making;
- development of active case manager roles;
- effective use of treatment plans; and the
- effective use of psychiatric advance directives, or other proxy decision-making arrangements where the substituted decision-maker is bound by the wishes of the patient.²²

In Convention terms, the goal of support is not merely to give voice to a patient's preferences or aspirations, but to facilitate open communication between the patient and the clinician with the goal of achieving full and informed consent.

What is required for free and informed consent?

The law of informed consent rests on the three requirements that the person is competent, informed and freely and voluntarily giving consent.²³ That is, the law assumes a 'rational' independent individual who is capable of making decisions in his or her own best interest without undue influence. Generally, when a person arranges and attends a medical consultation independently, it is assumed that the requirement of independence is met. Where a person is dependent upon others for transport or communication the assumption is easily displaced.

It is useful to look beyond the disability context to conceptualise the operation of clinical practices based on informed consent. Difficulty in assessing whether or not consent is freely and voluntarily given commonly arises in the provision of general medical treatment to young people. Practitioners who are skilled in the provision of health care to young people have developed practices that assess independence. For example, it is important to ensure that during a consultation where a 'support' person is present, time is spent alone with the young person to ascertain that the course of action proposed accords with their true wishes. The implementation of supported decision-

18. Bernadette McSherry, 'Opening Minds not Locking Doors', Address at the 50th Anniversary Public Lecture, Education 08 for Monash University, Melbourne, 9 October 2008 at <<http://www.law.monash.edu.au/rmh/50-anniversary.html>>. Law reform strategies that address the limitations of the outcome test include the promotion of advance directives. Advance directives are valued in this context because they assert the legal validity of decisions that are made while a person is demonstrably competent.

19. Dhanda, above n 9, 432.

20. Tina Minkowitz (Co-Chair, World Network of Users and Survivors of Psychiatry), Submission to the Committee on the Rights of Persons with Disabilities, Day of General Discussion on CRPD Article 12, 21 October 2009 at <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD21102009.aspx>>.

21. Ibid.

22. Penny Weller, 'Psychiatric Advance Directives and Human Rights' (2010) *Psychiatry, Psychology and Law* (forthcoming).

23. See Loane Skene, *Law and Medical Practice: Rights, Duties, Claims and Defences* (2nd ed, 2004).

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making strategies for people with mental illness will similarly require the development of clinical protocols that address the questions of independence and undue influence, to work toward the creation of a culture of patient-centred decision-making. At a minimum, the real involvement of at least one key person from outside the clinical team, who is nominated by and acceptable to the person with mental illness, is likely to assist in ensuring that the outcome of the supported decision-making process reflects the decisions that are acceptable to the person with mental illness.

The recognition that the imposition of involuntary medical treatment sits within the paradigm of torture or cruel, inhuman or degrading treatment imposes a high standard of care in relation to the achievement of free and informed consent. The amount of support necessary to ascertain the free and informed consent of persons with disabilities will vary from person to person, and will necessitate the development of strategies that provide a continuum of support from minimal to very high levels of support for a small minority.²⁴

Reasonable accommodation

The principle of 'reasonable accommodation' in Article 2 of the Convention, although yet to be tested, requires the provision of modifications and adjustments that enable a person to exercise their rights on an equal basis with others.²⁵ Reasonable accommodation is defined in Article 2 of the Convention as:

Appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

'Reasonable accommodation' in the Convention accords with similar notions in domestic anti-discrimination law such as reasonable adjustment or adaptation, and effective or suitable modifications or measures. For example, the *Australian Disability Discrimination Act 1992* (Cth) ('DDA') uses the term 'reasonable adjustment'. Employers are required to make 'reasonable adjustments' provided the adjustments do not impose an unjustifiable hardship or are unreasonable. Section 11 of the DDA sets out the factors that are to be taken into account in determining whether requiring a particular adjustment is reasonable. These are:

- nature of the benefit or detriment likely to accrue or be suffered by any persons concerned;

- effect of the disability of a person concerned; and
- financial circumstances and the estimated amount of expenditure required.²⁶

To afford a person 'reasonable accommodation' means to make adaptations in a health care facility that remove the barriers that prevent a person with a disability from participating in an activity or receiving services on an equal basis with others.²⁷ The limitation built into the notion of reasonable accommodation means that in some instances the level of support that is needed by a person may fall beyond what might be reasonably expected of a party to the Convention. Nevertheless, the standard required of State Parties will ultimately depend on the standard of medical care available in a given jurisdiction. In developed western health systems it is not unusual for very high levels of communicative support to be provided to person with communication deficits. It follows from the assumption of capacity, coupled with the principle of non-discrimination, that persons with mental illness should also be provided with high levels of support.

Alternative decision-making pathways

In cases where a person is not able to provide free and informed consent, despite the provision of appropriate support, it may be necessary to provide an alternative decision-making pathway.²⁸ Guidance on appropriate alternative decision-making pathways is found in Article 12(4) of the Convention.

Article 12(4) requires that 'all measures that relate to the exercise of legal capacity' provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. In particular, it requires that the safeguards ensure that measures relating to the exercise of legal capacity:

- respect the rights, will and preferences of the person;
- are free of conflict of interest and undue influence
- are proportional and tailored to the person's circumstances;
- apply for the shortest time possible, and
- are subject to regular review by a competent, independent and impartial authority or judicial body.

The safeguards must themselves be 'proportional to the degree to which such measures affect the person's rights and interests.'²⁹

These requirements reflect the Convention's strong emphasis on respect and support for the autonomy of the person. They describe a process of fully

24. Article 4(2) indicates that the economic, social and cultural rights in the Convention are subject to the principle of progressive realization.

25. Whether or not 'reasonable accommodation' has been provided is also relevant to a determination of whether the conduct in question was discriminatory, thereby involving Article 1 of the *Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, opened for signature 10 December 1984, 1465 UNTS 85 (entered into force 26 June 1987).

26. United Nations Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities* (2007) 60.

27. *Ibid.*

28. The term 'alternative decision-making' is used in contradistinction to the term 'substituted decision-making' which refers to processes where another or substitute person makes the decision on behalf of the person with a disability.

29. CRPD Article 12(4).

supported decision-making process, rather than an instance of substituted decision-making. The critical difference between the two is the privilege given in fully supported or alternative decision-making to the person's wishes and preferences. When a person is unable to make decisions, including medical decisions, there is a clear obligation to provide only those interventions that are in accordance with the preferences of the person, and to restore the person to capacity. Where the wishes and preferences of a person are not known, there is a dual obligation to provide immediate protective intervention, and to ascertain the wishes of the person. In this instance, if a protective treatment decision has been made, it must be modified once a person's (contrary) preferences are ascertained. Where it not possible to ascertain treatment preferences, intervention should be limited to providing such treatment as is necessary to return the person to a position where he or she can exercise control over treatment decisions. To the extent that decision-making arrangements accord with the requirements of Article 12(4), they will be acceptable under the Convention.

Substituted decision-making

As indicated above, the status of substitute decision is contentious. The core of the debate rests with the substance and effect of the decision-making process. Amita Dhanda argues that it is important to recognise the fluid and socially constructed nature of determinations of capacity, and the privilege that is accorded to the normative standard of cognitive capabilities.³⁰ She challenges the argument that substitute decision-making arrangements must be in place, albeit for a small percentage of persons, on the basis that the construction of a process to identify people who lack the requisite capacity will render the capacity of all persons with psychosocial disability open to question.³¹ Dhanda sees this as giving rise to a situation where a questionable advantage to a small group of people, will result in all people with psychosocial disabilities being disadvantaged, and argues therefore, that supported decision-making needs to displace guardianship in the legal constructions of capacity.³² She sees that 'human interdependence furthers the human rights of all persons' but 'the imposition of dependence is a negation of human aspiration, respect and choice.'³³

Recognition of the compatibility of human interdependence with autonomy is fundamental to understanding the approach that is adopted by the Convention.

Conclusion

The *Convention on the Rights of Persons with Disabilities* provides a basis for articulating new ethical standards that will contribute to systemic change. According to the Special Rapporteur on Torture and Other Cruel Inhuman or Degrading Treatment or Punishment, 'acceptance of involuntary treatment and involuntary

confinement runs counter to the provisions of the *Convention on the Rights of Persons with Disabilities*.³⁴

This article has sought to amplify the Special Rapporteur's analysis by arguing that the *Convention on the Rights of Persons with Disabilities* imposes an ethical obligation upon mental health practitioners to refrain from imposing involuntary medical treatment, and a duty upon legislatures to reflect this obligation in domestic laws. This does not mean that health professionals are restrained from intervening to protect the health and safety of person with mental illness. Rather, the standard of care envisaged by the Convention is one where interventions in times of acute crisis are humane, non-violent, and guided by the recognition that involuntary treatment is an affront to one's physical and mental integrity. This emphasises the importance of available, accessible and acceptable services, and the establishment of systems and protocols that encourage the early, voluntary participation of all persons who experience mental illness. Ultimately, the effect of Articles 12 and 17 is to position involuntary medical treatment, if it is considered at all, at the extreme end of a continuum of supported decision-making in health care practice that takes as its reference point the rights, wellbeing and autonomy of people with mental illness.

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30. Amita Dhanda, *Advocacy Note on Legal Capacity to the Committee on the Rights of Persons with Disabilities, Day of General Discussion on CRPD Article 12*, 21 October 2009 at <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD21102009.aspx>>.

31. *Ibid.*

32. *Ibid.*

33. *Ibid.*

34. Special Rapporteur on Torture, above n 13, [44].